Department of Defense Birth and Infant Health Registry: Birth Defects Among Infants Born to US Military Families: 2001 Annual Report

Tyler C. Smith, PhD, Anna T. Bukowinski, Ava Marie S.Conlin, Gia R. Gumbs, Isabel G. Jacobson, Robert J. Reed, Carter J. Sevick, Kathy J. Snell, Margaret A. K. Ryan

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Naval Health Research Center
140 Sylvester Rd.
San Diego, California 92106-3521

Department of Defense Birth and Infant Health Registry:

Birth Defects Among Infants Born to US Military Families

2001 Annual Report

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This report was prepared by the US Department of Defense Birth and Infant Health RegistryTeam. Visit the Naval Health Research Center Web site for additional information:

http://www.nhrc.navy.mil/department164/program.html

For more information about this report or other Registry activities, please contact:

Tyler C. Smith, MS, PhD
Department Head, Deployment Health Research
Naval Health Research Center
140 Sylvester Road
San Diego, CA 92106-3521
Email: NHRC-birthregistry@med.navy.mil

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This annual report contains provisional data for 2001 based on available DoD data and the National Birth Defects Prevention Network case definition list. Ongoing efforts to identify and validate cases may result in adjustments to these figures. Other publications using DoD Birth and Infant Health Registry data may reflect such adjustments

About the US Department of Defense Birth and Infant Health Registry

Location
The DoD Birth and Infant Health Registry is located at the DoD Center for Deployment Health Research at the Naval Health Research Center in San Diego, California. The DoD Birth and Infant Health Registry captures comprehensive data on health care utilization to calculate the prevalence of birth defects among children born to military families. Population-based electronic surveillance is supplemented by active case validation efforts.

Mission
The mission of the DoD Birth and Infant Health Registry is to (1) provide systematic surveillance of DoD beneficiary births and calculations of birth defects prevalence, (2) evaluate reproductive health outcomes to exposures of concern, and (3) conduct research to identify military- or deployment-specific risk factors that may affect infant health.

Surveillance
In 2001, the DoD Birth and Infant Health Registry captured data on the 92,707 live births that occurred in US military families worldwide. Data on birth defects were gathered using nationally standardized definitions for major congenital anomalies diagnosed before 1 year of age. These results complement civilian public health surveillance efforts, and may be especially valuable to military members and their families.

Benefits
The DoD Birth and Infant Health Registry captures targeted data through an active electronic medical records system. The Registry is one of the largest and most comprehensive birth defects surveillance systems in the United States, and it contributes to important national surveillance data. This report shows surveillance data for infants born to military families in 2001. More detailed analyses may be available in other publications.

Confidentiality
Information collected by the Registry is kept confidential using computer security measures and locked files and offices. All staff are required to sign a confidentiality agreement and receive annual training in confidentiality-protecting procedures. Violations of these procedures are grounds for immediate dismissal. Staff who leave the program remain under obligation to protect the confidentiality of all data collected as part of the program. Any uses of the data beyond those purposes defined in the original program require, at minimum, separate review by the Naval Health Research Center Institutional Review Board.

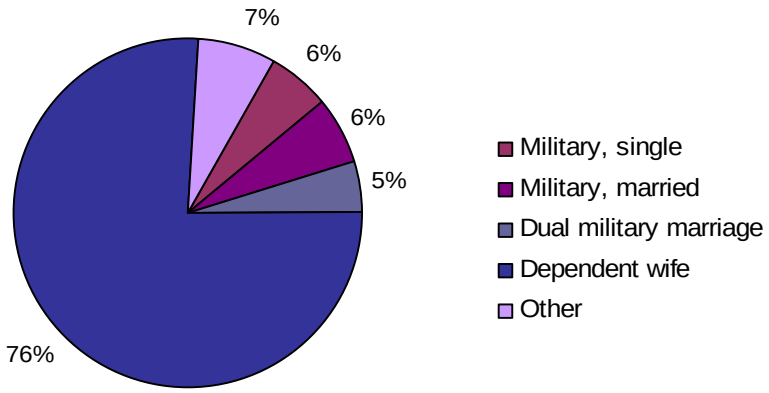
Text box:

The DoD Birth and Infant Health Registry is one of the largest and most comprehensive birth defects surveillance systems in the United States. It adds an important dimension to national surveillance data.

DoD Birth and Infant Health Surveillance

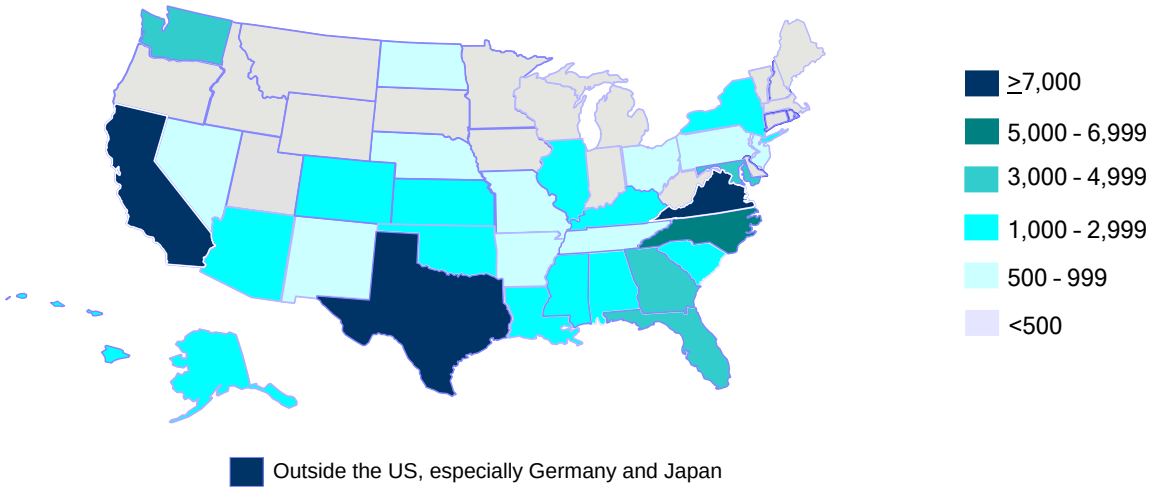
The U.S. Department of Defense (DoD) is challenged with monitoring and protecting the health and well-being of its service members. An important component of this challenge is the reproductive health of service members and their families, particularly in light of the stressors and exposures unique to military service. The DoD Birth and Infant Health Registry is a public health surveillance system that addresses reproductive issues in the DoD. Similar to other public health surveillance systems, the DoD Birth and Infant Health Registry monitors outcomes and identifies potential risk factors or exposures of concern. Although reproductive health issues affect both men and women, the growing proportion of women in the military (now greater than 14% of active-duty forces) further heightens awareness of the potential hazards military duty can place on reproductive health.

Maternal Military and Marital Status Among 2001 Births



The Registry is designed to capture DoD-sponsored live births of all gestational ages and birth weights. These births can occur at military or civilian medical facilities in all 50 states and the District of Columbia, and in more than 30 foreign countries. To be DoD sponsored, at least one parent must be a DoD health care beneficiary, such as an active-duty military member, active Reservist or National Guard member, military retiree, or other dependent. In 2001, the Registry captured 92,707 babies born to US military families around the world.

Approximate Number of Infants Born to Military Families in 2001 by Geographic Location



Birth defects and other outcomes of interest are identified by reviewing inpatient and outpatient encounters in the first year of life for all births captured in the Registry. The codes used to identify birth defects are consistent with state birth defects surveillance programs, enabling the calculation of the prevalence of birth defects in all major malformation categories. The DoD Birth and Infant Health Registry reports birth defects surveillance data annually in DoD reports, as well as to the National Birth Defects Prevention Network (NBDPN).

Data Sources

- The Standard Inpatient Data Record system represents hospitalizations at military medical facilities, with up to eight discharge diagnoses coded from the *International Classification of Diseases*, 9th Revision, Clinical Modification (ICD-9-CM) diagnostic system.
- The Standard Ambulatory Data Record system represents all outpatient encounters at DoD medical facilities, with up to four ICD-9-CM-coded diagnoses.
- The DoD TRICARE insurance system maintains complete records with ICD-9-CM-coded diagnoses for DoD-financed health care (inpatient or outpatient) at civilian medical facilities.

The DoD's ability to capture records of health care encounters, both inpatient and outpatient, from virtually any medical facility worldwide, is analogous to a large managed care organization. DoD codes health care data with the military member's social security number. These data can be easily linked to demographic- and service-related information on active-duty members in the Defense Enrollment Eligibility Reporting System and the Defense Manpower Data Center. Such data can provide important profiles of military parents, including deployment and occupational exposure histories that may be relevant to birth defects research.

Text box:

The DoD's ability to capture records of health care encounters, both inpatient and outpatient, from virtually any medical facility worldwide, is analogous to a large managed care organization.

Definitions of Birth Defects

According to the NBDPN, birth defects are conditions that can result in physical malformations, sensory deficits, chromosomal abnormalities, metabolic defects, neurodevelopmental disorders, and complications related to prematurity and low birth weight, among others. Birth defects range in severity from mild to major, and can be diagnosed during pregnancy, at birth, or at any time after birth. Most often, birth defects are identified within the first year of life. The DoD Birth and Infant Health Registry monitors the 45 major birth defect diagnoses outlined in the NBDPN Guidelines. Infant health encounters are monitored through the first year of life to ensure ample time for the discovery and diagnosis of birth defects.

Birth Defects Included in the Case Definition of DoD Birth and Infant Health Registry			
Birth Defect	ICD-9-CM Code	Birth Defect	ICD-9-CM Code
Central Nervous System		**Orofacial**	
Anencephalus	740.0-740.1	Choanal atresia	748.0
Spina bifida w/o anencephalus	741.0, 741.9 w/o 740.0-740.10	Cleft palate	749.0
Encephalocele	742.0	Cleft lip with, w/o cleft palate	749.1, 749.2
Microcephalus	742.1	**Gastrointestinal**	
Hydrocephalus w/o spina bifida	742.3 w/o 741.00, 741.9	Tracheosophageal fistula, esophageal atresia	750.3
Eye		Rectal and large intestinal atresia/stenosis	751.2
Anophthalmia/microphthalmia	743.0, 743.1	Pyloric stenosis	750.5
Congenital cataract	743.30-743.34	Hirshsprung's disease	751.3
Aniridia	743.45	Biliary atresia	751.61
Ear		**Genitourinary**	
Anotia/microtia	744.01, 744.23	Hypospadias and epispadias (males)	752.61, 752.62
Cardiovascular		Renal agenesis/hypoplasia	753.0
Common truncus	745.0	Obstructive genitourinary defect	753.2, 753.6
Transposition of great arteries	745.10, .11, .12, .19	Bladder exstrophy	753.5
Tetralogy of Fallot	745.2	**Musculoskeletal**	
Ventricular septal defect	745.4	Congenital hip dislocation	754.30, .31, .35
Atrial septal defect	745.5	Reduction deformity, upper limbs	755.20-755.29
Endocardial cushion defect	745.60, .61, .69	Reduction deformity, lower limbs	755.30-755.39
Pulmonary valve atresia/stenosis	746.01, 746.02	Anomolies of diaphragm	756.6
Tricuspid valve atresia, stenosis	746.1	Anomolies of abdominal wall	756.79
Ebstein's anomaly	746.2	**Chromosomal**	
Aortic valve stenosis	746.3	Down syndrome (Trisomy 21)	758.0
Hypoplastic left heart syndrome	746.7	Trisomy 13	758.1
Patent ductus arteriosus	747.0	Trisomy 18	758.2
Coarctation of aorta	747.10	**Other**	
		Fetal alcohol syndrome	760.71

Characteristics of Infants in the DoD Birth and Infant Health Registry

	Live Births	Any Birth Defect*	% Any Birth Defect*
Total	92,707	4,453	4.80
Sex of infant			
Male	47,583	2,535	5.33
Female	45,124	1,918	4.25
Maternal age in years			
13 - 19	7,629	305	4.00
20 - 24	32,041	1,572	4.91
25 - 29	24,570	1,197	4.87
30 - 34	17,001	796	4.68
35 - 39	6,895	375	5.44
>39	1,285	76	5.91
Unknown	3,286	132	4.02
Maternal military and marital status			
Military, single	6,171	304	4.93
Military, married	5,404	266	4.92
Dual military marriage	4,573	198	4.33
Dependent wife	70,100	3,479	4.96
Other	6,459	206	3.19
Race/ethnicity of military sponsor			
White	57,662	2,915	5.06
Black	16,715	776	4.64
Hispanic	8,074	362	4.48
Asian	3,161	127	4.02
Unknown	7,095	273	3.85
Branch of service of sponsor			
Army	32,774	1,623	4.95
Navy	23,401	1,171	5.00
Air Force	21,489	994	4.63
Marines	10,334	509	4.93
Unknown	4,709	156	3.31
Pay grade of sponsor†			
E1 - E3	17,037	834	4.90
E4 - E6	50,825	2,448	4.82
E7 - E9	4,491	225	5.01
O1 - O3	10,407	529	5.08
O4 - O9	4,453	229	5.14
W1 - W5	776	31	3.99
Unknown	4,718	157	3.33
Singleton or multiple births			
Singleton	90,004	4,220	4.69
Multiple	2,703	233	8.62

*Excludes patent ductus arterious and atrial septal defects among preterm births.
†E indicates enlisted; O, officer; and W, warrant officer.

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Consistent with the general US population, the overall percentage of any defect among infants captured in the DoD Birth and Infant Health Registry was 4.80% in 2001. As in the general US population, rates of any defect increase with maternal age.

DoD Birth Defect Rates, 2001

Type of Birth Defect	Estimated Rate per 1,000 Live Births
Central nervous system	4.37
Eye	0.77
Ear	0.28
Heart*	12.69
Respiratory	0.35
Cleft lip/palate	1.84
Upper alimentary	3.42
Digestive system	1.49
Male reproductive (based on male births)	10.93
Urinary	4.16
Musculoskeletal/limb	6.35
Gastroschisis/omphalocele	1.32
Chromosomal	1.84
Fetal alcohol syndrome	0.08

*Excludes patent ductus arterious and atrial septal defect among preterm births.

It is known that genetic factors, environmental pollutants, occupational hazards, dietary factors, medications, and personal behaviors all can contribute to the development of certain types of birth defects. For example, insufficient levels of maternal folic acid prior to or in the early months of pregnancy are a risk factor for neural tube defects. However, many birth defects do not have a known cause. Among infants captured in the DoD Birth and Infant Health Registry in 2001, the overall percentage of any defect is 4.80%, which is consistent with what is seen in the general US population. Also similar to the general US population, rates of any defect increase with maternal age.

Specific defects or defect categories differ greatly in their occurrence. It is difficult to determine what impact, positive or negative, universal access to standardized medical care has on the collection of these data. Free access to quality care may make the diagnosis of birth defects more likely, which would result in rates for specific defects that appear higher than what occurs in the civilian population.

Major structural anomalies should not be affected by these differences in access to care, but relatively minor defects, such as atrial septal defect, may go unnoticed throughout the infant's first year of life. The safest use of these data is to look for changes in the occurrence of specific defects among DoD health care beneficiaries.

Validation

Validation of infant diagnoses captured in the DoD Birth and Infant Health Registry is essential to the integrity of this large electronic surveillance system. To develop the analytic database, validation efforts included the identification and removal of multiple entries for the same diagnoses in the same infant, and accurate identification of multiple births to the same sponsor.

The resulting database includes only one birth entry for each child born to a military family in the surveillance period.

To assess potential under-reporting, over-reporting, or miscoding of electronic diagnostic data, active case validation was performed at one of the DoD's largest health care facilities—the Naval Medical Center San Diego. DoD Birth and Infant Health Registry professionals reviewed inpatient and outpatient records with electronic data to identify cases that may have been miscoded based on standardized coding used by other birth defects researchers.

Limitations

As with most other birth defects registries, the DoD system cannot capture data on pregnancy terminations, miscarriages, or stillbirths. Other limitations associated with the DoD Registry include its reliance on ICD-9-CM coding for diagnosing birth defects. The active case validation efforts can only partially mitigate this challenge. Additional limitations may be related to the dynamics of the changing military population. Eligibility for DoD care at birth may not correspond to eligibility at the time of conception and pregnancy. Some children conceived before a parent's active-duty service may be represented in the DoD Birth and Infant Health Registry; some children conceived on active duty may be born outside of the DoD system if a member leaves the service or uses an alternative insurance system.

Strengths and Future Directions

The DoD Birth and Infant Health Registry completely captures its intended data through an active electronic medical records system. The DoD Registry is one of the largest and most comprehensive birth defects surveillance systems in the United States, and it contributes to important national surveillance data. This report documents surveillance data for infants born to military families in 2001; more detailed analyses may be available in other publications.

Research Projects

In addition to birth defects, the DoD Birth and Infant Health Registry is capable of researching several facets of reproductive health. Included in this report is a list of publications and abstracts for the year 2001. Please contact the Birth Registry team at NHRC-birthregistry@med.navy.mil for a complete list of publications and scientific abstracts.

Publications

2001

Ryan MAK, Pershyn-Kisor MA, Honner WK, Smith TC, Reed RJ, Gray GC. The Department of Defense Birth Defects Registry: overview of a new surveillance system. Teratology 2001;64 (S1): S26-9.

Bush RA, Smith TC, Honner WK, Gray GC. Active surveillance of birth defects among US Department of Defense beneficiaries: a feasibility study. Mil Med 2001;166:179-83.

Scientific Abstracts

2001

Aran R, Honner WK, Kaufman SA, Reed RJ, Smith TC, Hooper TI, King JC, Ryan MAK. Cardiac birth defects evaluated in the Department of Defense Birth and Infant Health Registry. National Birth Defects Prevention Network meeting, 11-15 Nov 2001, Orlando, FL.

Kaufman SA, Honner WK, Reed RJ, Smith TC, Aran R, King JC, Ryan MAK. Quality of data in the Department of Defense Birth and Infant Health Registry. National Birth Defects Prevention Network meeting, 11-15 Nov 2001, Orlando, FL.

Kaufman SA, Honner WK, Reed RJ, Smith TC, McKeehan JA, King JC, Gray GC, Ryan MAK. The value of active case validation in the Department of Defense Birth Defects Registry. 41st Navy Occupational Health and Preventive Medicine Workshop, 12-17 May 2001, San Diego, CA.

Kaufman SA, Honner WK, Reed RJ, Smith TC, Aran R, King JC, Ryan MAK. Quality of data in the Department of Defense Birth and Infant Health Registry. 41st Navy Occupational Health and Preventive Medicine Workshop, 12-17 May 2001, San Diego, CA.

Ryan MAK. The Department of Defense Birth Defects Registry. Conference on Illnesses among Gulf War Veterans: Uniformed Services University of the Health Sciences Faculty Senate Research Day, 10-11 Apr 2001, Bethesda, MD.

Honner WK, Smith TC, Reed RJ, McKeehan JA, Ryan MAK, Hooper TI. The Department of Defense Birth Defects Registry: methodological considerations. Conference on Illnesses among Gulf War Veterans: Uniformed Services University of the Health Sciences Faculty Senate Research Day, 10-11 Apr 2001, Bethesda, MD.

Honner WK, Smith TC, Reed RJ, McKeehan JA, Ryan MAK, Gray GC. The Department of Defense Birth Defects Registry: methodological considerations. 4th Annual National Birth Defects Prevention Network Meeting, 29-31 Jan 2001, San Antonio, TX.

Ryan MAK, Honner WK, Reed RJ, Smith TC, Kaufman SA, McKeehan JA, King JC, Gray GC. The value of active case validation in the Department of Defense Birth Defects Registry, 4th Annual National Birth Defects Prevention Network Meeting, 29-31 Jan 2001, San Antonio, TX.

Ryan, MAK. The Department of Defense Birth Defects Registry. Conference on Illnesses among Gulf War Veterans: A Decade of Scientific Research, 24-26 Jan 2001, Washington, DC.

Ryan MAK, Honner WK, Reed RJ, Smith TC, Kaufman SA, McKeehan JA, King JC, Gray GC. The value of active case validation in the Department of Defense Birth Defects Registry. Conference on Illnesses among Gulf War Veterans: A Decade of Scientific Research, 24-26 Jan 2001, Washington, DC.

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6. AUTHORS Tyler C**.** Smith, MS, PhD; Anna T. Bukowinski, MPH; Ava Marie S. Conlin, DO, MPH; Gia R. Gumbs, MPH; Isabel G. Jacobson, MPH; Robert J. Reed, MA; Carter J. Sevick, MS; Kathy J. Snell Margaret A.K. Ryan, MD, MPH

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Commanding Officer
Naval Health Research Center
140 Sylvester Rd
San Diego, CA 92106-3521

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Commanding Officer
Naval Medical Research Center
503 Robert Grant Ave
Silver Spring, MD 20910-7500

Commander
Navy Medicine Support Command
P.O. Box 140
Jacksonville, FL 32212-0140

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14. ABSTRACT

The DoD Birth and Infant Registry provides systematic surveillance of DoD beneficiary births, evaluates reproductive outcomes, and conducts research to identify military-or deployment-specific risk factors that might significantly effect infant health. The Registry monitors the 45 major birth defects diagnoses outlined in the National Birth Defects Prevention Network. In 2001, the Registry recorded 92,707 births to US military families around the world. The overall birth defect rate for 2001 was 4.80%, which is consistent with what is seen in the general US non-military population. The DoD Birth and Infant Health Registry is one of the largest and most comprehensive birth defects surveillance systems in the United States. It monitors outcomes and indentifies potential risk factors or exposures of concern to military families and makes an important contribution to the national surveillance data.

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